

Dying With Dementia in Long-Term Care

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Purpose: To better understand the experiences and potential unmet need of persons who die in long-term care. **Design and Methods:** We conducted after-death interviews with staff who had cared for 422 decedents with dementia and 159 who were cognitively intact and received terminal care in U.S. nursing homes (NHs) or residential care-assisted living (RC-AL) settings. We conducted family caregiver interviews for 293 decedents. **Results:** We noted no differences between decedents with and without dementia in terms of pain, psychosocial status, family involvement, advance care planning, most life-prolonging interventions, and hospice use. Dying residents with dementia tended to die less often in a hospital, have less shortness of breath, receive more physical restraints and sedative medication, and use emergency services less frequently on the last day of life. Persons with dementia dying in RC-AL settings tended to have more skin ulcers and poorer hygiene care than nondemented persons in RC-AL settings. In comparison with persons dying with dementia in NHs, those in RC-AL settings tended to be restrained less often, have emergency services called more often on the day of death, and have family more satisfied with physician communication. **Implications:** These results suggest that the overall quality of care for

persons dying with dementia in long-term-care settings may not differ markedly from that provided to persons who are cognitively intact. Similarly, large discrepancies in the overall quality of palliative care for persons with dementia in RC-AL facilities and NHs were not identified. However, numerous specific areas for care improvement were noted.

Key Words: *Assisted living, End-of-life care, Nursing homes, Palliative care, Residential care facilities*

Each day, approximately 1,000 nursing home (NH) residents and 500 residential care-assisted living (RC-AL) residents die (Centers for Disease Control, 2002; National Center for Assisted Living, 2001; Zimmerman et al., 2005). Given that more than one half of NH and RC-AL residents have dementia (Magaziner et al., 2000; Zimmerman et al., 2007), long-term-care facilities are a major site for end-of-life care of persons with dementia. Indeed, because persons with dementia have a prolonged need for high levels of care, it is estimated that 70% of such persons spend their last days in residential long-term care (Mitchell, Teno, Miller, & Mor, 2005). Therefore, the provision of end-of-life services for persons with dementia is a major component of long-term care.

It is likely that the end-of-life services required by persons with dementia differ from those of persons who die from other conditions. Dementia is slowly progressive over many years, and family and health care providers may not always view it as a terminal illness. Caregivers may overlook prognostic signs that otherwise could trigger end-of-life planning (Sachs, Shega, & Cox-Hayley, 2004), and even Medicare hospice guidelines may fall short of the prognostic information needed to understand the course of dementia (Schonwetter et al., 2003). Furthermore, persons with dementia often die from acute illnesses superimposed on dementia (e.g., pneumonia), rather than from the dementia alone. Thus, planning and preparation for end-of-life care for patients with dementia differs from that for patients with illnesses better understood as terminal, such as end-stage organ

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Table 1. Domains and Variables Evaluated

Domains	Sample Variables or Variable Categories	Source
Descriptive data	Course of illness	Staff
Family involvement	Family involvement	Family
	Family involvement in basic care	
	Most influential person in care decisions	
Communication with residents and family	Physician contact with family	Family
Decision making	Physician communication with family	
	Advance care planning	Family
	Decision making regarding interventions	
Satisfaction with care	Family global impressions of care	Family
Physical symptoms	Pain, shortness of breath, hygiene, and skin ulcers	Staff
Behavioral symptoms and treatment	Management of behavioral symptoms	Staff
Psychosocial status	Appeared at peace, received compassionate touch, dignity maintained, attached to staff	Staff
Care provision	Life-sustaining interventions (intravenous fluids, feeding tube, hospitalization, antibiotics, cardiopulmonary resuscitation, 911 on last day of life)	Staff
	Palliative interventions (moving or positioning, hospice services)	
	Symptom-directed care	
Care of the imminently dying patient	Circumstances of death	Staff

Note: The sources for the domains of end-of-life experience and care evaluated are as follows: For family involvement, and for communication with residents and family, the Alzheimer's Association (2007); for decision making, the Alzheimer's Association as well as Ferrell (2005), Mitchell (2004), and the National Consensus Project (2004); for satisfaction with care, Volicer (2001); for physical symptoms, all aforementioned references; for behavioral symptoms and treatment, psychosocial status, and care provision, the Alzheimer's Association, Ferrell, Mitchell, and the National Consensus Project; for care of the imminently dying patient, the National Consensus Project.

failure or metastatic cancer. In addition, the presence of prolonged cognitive impairment can result in surrogate decision makers who have varying levels of familiarity with individual patient preferences (Bradley, Peiris, & Wetle, 1998).

Given the relative paucity of research data on this highly prevalent and complex population, a better understanding of the experience of persons with dementia who die in long-term-care facilities is critical to providing optimal end-of-life care in these settings. A recent systematic review yielded only four clinical trials of palliative care approaches for this population (Sampson, Ritchie, Lai, Raven, & Blanchard, 2005). Since then, Engel and colleagues conducted a study of end-of-life care for NH residents with advanced dementia in 13 Boston facilities; they reported that better family communication, improved comfort, avoidance of tube feeding, and specialized dementia care were associated with greater family caregiver satisfaction (Engel, Kiely, & Mitchell, 2006). However, no large studies have examined the quality of end-of-life care in long-term care for dementia patients compared with those who die without dementia. Furthermore, studies of end-of-life care in RC-AL facilities are largely absent, in spite of the growing importance of this facility type in providing both dementia care and end-of-life care (Sloane et al., 2003).

Therefore, to better understand the experiences and potential unmet needs of persons with dementia who die in long-term care, and of the family members who care for them, we conducted and analyzed data from staff and family caregiver interviews regarding 581 persons who had lived in a NH or RC-AL

community. Our conceptual and analytical framework represents expert opinion on the essential domains of the experience of dying and the provision of palliative care. Domains and variables represented by this framework are drawn from the work of the Alzheimer's Association (2007), Ferrell (2005), Mitchell, Kiely, and Hamel (2004), the National Consensus Project for Quality Palliative Care (2004), and Volicer, Hurley, and Blasi (2001). Table 1 summarizes the domains we evaluated.

Through our analyses we sought to address two primary research questions: First, how does the experience of dying and the provision of palliative care for long-term-care residents with dementia and their families differ from that of those without dementia? Second, how does the experience of dying and the provision of palliative care for persons with dementia and their families differ, depending on whether the decedent resides in a NH or RC-AL community?

Methods

Study Sample

We derived the data for these analyses from a stratified random sample of 199 RC-AL communities and 31 NHs recruited from four states (Florida, Maryland, North Carolina, and New Jersey). We initially established the facility cohort, known as the Collaborative Studies of Long-Term Care (CS-LTC), in 1996 and refreshed it for this study to reflect the attrition of old facilities and the opening of new facilities between 1996 and 2002. We

chose the four study states to reflect the diversity of state policies toward RC-AL, in terms of licensure, structure, and process of care. Within each state, we selected participating facilities in four strata: NHs, RC-AL facilities with fewer than 16 beds, so-called new-model RC-AL facilities (≥ 16 beds, built after 1987, and having one or more features suggesting the ability to care for an impaired population), and traditional RC-AL facilities (≥ 16 beds, but not new model). Further details on the facility categorization process in the CS-LTC are published elsewhere (Zimmerman, Sloane, & Eckert, 2001).

Between July 2002 and January 2005, research staff telephoned participating facilities monthly to identify residents who had died. To achieve a balance of sample size across facility sizes and types, we had the sample accrual period vary by facility type (shortest for NHs, and longest for RC-AL facilities with < 16 beds). These monthly telephone contacts identified all former facility residents who had died in the past month and who met the study's inclusion criteria: (a) having spent 15 of the last 30 days of life in a study facility, and (b) having died no more than 3 days after leaving the facility.

For each identified death, research staff asked the participating facility to identify two individuals who would be approached for interviews: (a) a staff respondent, defined as the facility staff member who had known the resident best and either provided or supervised direct care, and (b) the family respondent, defined as the blood relative, legal guardian, or friend who was most involved in care during the resident's last month of life and had visited or spoken with the resident or a staff member at least once during the last month of the resident's life.

To recruit staff respondents, we had the project office contact them by telephone and request participation in the study interview. If the contacted staff member agreed to be interviewed, then the interview was scheduled at a time that was convenient for the staff member. To recruit family respondents, we sent letters to family members approximately 8 weeks following the resident's death, after which time we had the family respondent contacted by telephone to schedule an interview.

Of the 1,020 eligible deaths identified, we collected interview data on 792 decedents. These included staff interviews for 677 decedents and family interviews for 451. Both participating staff and family informants provided informed consent by telephone at the beginning of their interviews; we used procedures that were approved by the Institutional Review Board of the University of North Carolina at Chapel Hill. Interviews lasted 45 to 90 minutes for family members and 30 to 45 minutes for staff members.

We defined a decedent as a person having died with dementia if the NH or RC-AL staff member who knew the individual best responded "yes" to both of the following questions: (a) "Three months prior to death was [the decedent] an Alzheimer's

type resident?" and (b) "Was dementia a contributing factor to [the decedent's] death?" We defined a decedent as a person having died without dementia if the staff respondent answered "no" to both of the aforementioned questions. We excluded from our analyses the 84 respondents (12.6%) for whom one question was answered "yes" and the other "no" (i.e., for whom dementia status was uncertain), and we excluded 12 for whom this information was incomplete. Thus, this article describes staff-reported results on 581 decedents, of whom 422 are defined as having had dementia and of whom 159 are defined as having been cognitively intact during the last months of life. Family interview data were available for 293 (50.4%) of these residents.

Study Measures

Because the study sought to gather data on both the experience of dying and the provision of palliative care, our data-collection strategy was to obtain data from the person (i.e., staff or family respondent) who would be most capable of providing valid data in a given domain. Thus, we used staff interviews to characterize the following aspects of decedent end-of-life status: illness course, physical symptoms, behavioral symptoms and treatment, psychosocial status, care provision, and care of the imminently dying patient. Similarly, family interviews were the source of data on family involvement, communication with the residents and family, decision making (including advance care planning), and satisfaction with care. In addition, we gathered data on demographic characteristics of the decedents (age, gender, race or ethnicity, marital status, religion, Medicaid status, and relationship to the family respondent) from family interviews or facility staff, as appropriate. Table 1 provides an overview of the domains, variables, and sources used to gather data.

To evaluate physician-family communication, we used an established scale: the seven-item Family Perception of Physician-Family Caregiver Communication scale (Biola et al., 2007). Items in this scale include whether the family was kept informed, received information about what to expect, understood what the doctor was saying, discussed wishes for medical treatment, had the opportunity to ask questions, felt listened to, and felt understood; responses ranged from 0 (poor) to 3 (excellent) and had a Cronbach's alpha of $\alpha = 0.96$.

Analytical Methods

We used simple descriptive statistics to characterize the sample with respect to facility type and state, resident demographics, and relationship of family respondent, both overall and by dementia status. In order to compare those with and without dementia, we used logistic regression with dementia status as

the binary dependent variable and the characteristic of interest as the single independent variable. We applied generalized estimating equations to the logistic regression in order to account for the clustering of residents within facilities (Diggle, Heagerty, Liang, & Zeger, 2002). We specified an exchangeable correlation matrix as the working correlation structure, as is commonly done in clustered cross-sectional data such as these (Preisser & Koch, 1997); the empirical “sandwich” estimators are robust to misspecification of the correlation matrix (Liang & Zeger, 1986). Further, because the study design was stratified by facility type and because important aspects of dementia care may differ between NHs and RC-AL facilities, we also compared the same factors for decedents with dementia and their families by type of long-term-care setting. We also conducted these analyses by using generalized estimating equations applied to logistic regression models; however, here the measures of the end-of-life experience were the dependent variables (with a separate model for each), and dementia status and facility type (NH vs RC-AL) were the two independent variables included in all models, with the models comparing facility type limited to the dementia group.

Because the relationship between dementia status and end-of-life care and family experiences may differ depending on the setting, we also tested a Facility Type \times Dementia Status interaction term in each model. In almost all cases, this was not significant ($p > .05$) and we dropped the interaction. In those instances in which there was evidence for interaction, we made the comparisons for dementia status separately for NH and RC-AL decedents.

To account for policy variation among states, and key resident characteristics that vary between NHs and RC-AL facilities, we adjusted our statistical tests for differences for state, decedent age, and functional status, with functional status operationalized as the number of activity of daily living (ADL) tasks, among transferring, walking, and eating, in which the resident depended on personal assistance 3 months before his or her death. Because our study makes multiple comparisons, our discussion only draws conclusions regarding findings whose statistical tests were significant at $p \leq .01$, and we make special note of differences that were significant at $p < .002$, which is in accord with a strict Bonferroni correction. We conducted all analyses by using SAS Version 9.1.3.

Results

Demographics

Table 2 provides demographic data on the 581 decedents in the study sample, overall and by dementia status. Just over half (54%) were from NHs; the mean length of stay in the long-term-care

facility from which they were recruited was 28.7 months. Study decedents were largely White and unmarried, and they were predominantly female. Approximately three fourths (73%) had dementia.

Gender, race or ethnicity, marital status, religion, Medicaid status, and length of stay did not differ by dementia status. However, persons with dementia were more likely to have had greater ADL dependency ($p < .001$), and to have had a family informant who was a spouse or child ($p = .002$).

Experience of Dying and Palliative Care: Dementia Versus Nondementia

Table 3 displays data on the dying experience and palliative care received by decedents with and without dementia, as reported by facility staff, stratified by site of care (RC-AL facility or NH); Table 4 displays data from family respondent reports, also stratified by site of care. Within each table the first p -value column displays the adjusted p value of the comparison between persons who died with dementia and those who died without dementia, regardless of site. The second p value refers to the adjusted comparison across facility types only for those with dementia.

When we examined staff reports of physical symptoms (Table 3), we noted no difference between persons with and without dementia in reported levels of pain or effectiveness of pain treatment. Shortness of breath, however, was both more often present and more often inadequately treated among decedents without dementia ($p = .014$). When we examined reports of hygiene care, we noted an interaction, in that care was reported to be significantly more effective for persons without dementia in RC-AL facilities ($p = .004$), whereas the opposite was noted for NHs ($p = .024$). An interaction effect was also present in reports of skin ulcer prevalence; in RC-AL facilities, skin ulcers were considerably more prevalent among persons with dementia (27% vs 10%; $p = .003$), whereas in NHs no significant difference was present ($p = .566$). Finally, we noted that, across all settings and comparisons, the use of physical restraints and sedative medications was more common among persons with dementia than those without.

When we compared the use of life-sustaining and palliative interventions, we noted no significant differences between demented and nondemented residents in the use of nutritional supplements, intravenous fluids, feeding tubes, hospitalization, antibiotics, in-facility cardiopulmonary resuscitation, special attention to moving and positioning, or hospice use (Table 3). Facilities tended to more frequently call 911 on the last day of life for persons without dementia ($p = .006$), and persons without dementia—particularly if they were RC-AL resi-

Table 2. Description of the Study Sample, Overall and According to Dementia Status of the Decedent

Item	Overall		Decedents With Dementia		Decedents Without Dementia		<i>p</i>
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	
Facility type							
RC-AL	267	46.0	175	41.5	92	57.9	.006
Nursing home	314	54.0	247	58.5	67	42.1	
State							
Florida	141	24.3	93	22.0	48	30.2	.543
Maryland	131	22.5	100	23.7	31	19.5	
North Carolina	147	25.3	106	25.1	41	25.8	
New Jersey	162	27.9	123	29.1	39	24.5	
Gender							
Male	181	31.2	132	31.3	49	30.8	.747
Female	400	68.8	290	68.7	110	69.2	
Age: <i>M, SD</i>	85.7	9.1	86.5	7.8	83.6	11.7	.019
Race/Ethnicity							
White, non-Hispanic	517	89.1	381	90.3	136	86.1	.304
White, Hispanic	12	2.1	9	2.1	3	1.9	
African American	49	8.4	30	7.1	19	12.0	
Other	2	0.3	2	0.5	0	0.0	
Marital status							
Married	49	17.3	39	19.1	10	12.5	.170
Unmarried	235	82.7	165	80.9	70	87.5	
Religion							
Protestant	156	55.5	108	53.7	48	60.0	.610
Catholic	80	28.5	58	28.9	22	27.5	
Jewish	21	7.5	16	8.0	5	6.3	
Other	8	2.8	7	3.5	1	1.3	
None	16	5.7	12	6.0	4	5.0	
On Medicaid during last year							
No	172	61.0	121	58.7	51	67.1	.128
Yes	110	39.0	85	41.3	25	32.9	
Relationship of family respondent							
Spouse	24	8.3	22	10.5	2	2.5	.002
Adult child (or in-law)	195	67.2	147	70.3	48	59.3	
Other	71	24.5	40	19.1	31	38.3	
Length of stay in months: <i>M, SD</i>	28.7	33.1	29.4	33.7	26.8	31.2	.216
ADL dependencies: <i>M, SD</i>	1.7	1.2	1.9	1.2	1.0	1.1	<.001

Note: For the study sample, $N = 581$; for decedents with dementia, $n = 422$; for decedents without dementia, $n = 159$. Missing data are as follows: race or ethnicity ($n = 1$); marital status ($n = 297$); religion ($n = 300$); Medicaid status ($n = 299$); and family relationship ($n = 291$). All those with large numbers of missing data are from the family interview, which is unavailable for 288 (49.6% of sample), including 211 with dementia and 77 without. The proportion having family data available does not differ between those with (211/422 = 50.0%) and without (82/159 = 51.6%) dementia, $p = .472$. The p value is a Type 3 score test p value for comparison of decedents with and without dementia, based on logistic regression, using generalized estimating equations to account for clustering of residents within facilities. ADL = activity of daily living; ADL dependencies are in walking, transferring, and eating. All values are shown as number or percentages, except for age, length of stay, and ADL dependencies, which are shown as means and standard deviations.

dents—were more likely to die in the hospital than were persons with dementia ($p = .005$).

Domains reported by family informants (Table 4) demonstrated relatively few differences by dementia status. Across all aspects of interaction and care other than telephone use, family involvement was not different for decedents with dementia, when compared with those who did not have dementia. Although residents with dementia were less able to participate in decisions about care ($p > .001$), and death and dying tended to be less frequently

discussed with persons with dementia ($p = .030$), all other aspects of advance care planning—including prevalence of a living will, of a durable power of attorney (POA) for health care decisions, and decision making about cardiopulmonary resuscitation, feeding tubes, or comfort measures—did not differ by dementia status. Family familiarity with the physician, and the prevalence of meetings between the family and physician, did not differ by dementia status; however, there was a trend ($p = .035$) for families of decedents without demen-

Table 3. Experience of Dying and Palliative Care Reported by Staff of Residents Who Died With and Without Dementia in RC-AL Communities and NHs

Item	RC-AL Facility				NH				<i>p</i> Value of Comparison by	
	Decedents With Dementia		Decedents Without Dementia		Decedents With Dementia		Decedents Without Dementia			
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	Dementia Status	Facility Type
Course of illness during last months of life										
Stable health	22	12.6	25	27.2	20	8.1	6	9.0	.212	.136
Steady decline	93	53.4	43	46.7	177	71.7	48	71.6		
Series of ups and downs	59	33.9	24	26.1	50	20.2	13	19.4	.225	<.001
Physical symptoms and symptom-directed care during last month of life										
Pain ^a										
Not effectively treated	17	10.2	4	4.5	13	5.5	3	4.6	.078	.186
Treatment effective	69	41.3	44	49.4	133	55.9	44	67.7		
None, never an issue	81	48.5	41	46.1	92	38.7	18	27.7	.206	.249
Shortness of breath ^a										
Not effectively treated	8	5.0	13	15.7	13	5.3	8	12.3	.014	.570
Treatment effective	60	37.3	34	41.0	108	44.4	29	44.6		
None, never an issue	93	57.8	36	43.4	122	50.2	28	43.1	.014	.218
Hygiene care very effective	153	89.5	87	96.7	224	90.7	52	77.6	*	*
One or more skin ulcers	47	26.9	9	9.9	55	22.6	17	25.4	*	*
Management of behavioral symptoms										
Any restraints used	115	65.7	35	38.0	226	91.5	49	73.1	.004	<.001
Any restraints other than partial bed rails used	81	46.3	16	17.4	167	67.6	32	47.8	.002	.031
Sedative used frequently	33	21.0	10	11.0	68	29.2	9	14.1	.010	.592
Sedative used at least sometimes	47	29.9	11	12.1	87	37.3	14	21.9	.002	.792
Psychosocial status during last month of life										
Resident appeared to be at peace	122	70.1	73	82.0	158	64.2	42	62.7	.163	.304
Resident received compassionate touch daily	168	96.6	82	90.1	233	95.1	60	89.6	.035	.399
Resident's dignity maintained	156	90.2	82	90.1	219	89.4	57	85.1	.676	.847
At least one staff had close attachment to resident	144	82.8	77	85.6	176	72.1	55	83.3	.220	.528
Life-sustaining interventions during the last month of life ^b										
Nutritional supplement	98	68.1	34	58.6	184	87.6	43	87.8	.170	.003
IV fluids	6	4.2	3	5.2	24	11.4	5	10.2	.499	.014
Feeding tube	2	1.4	2	3.4	16	7.5	6	12.0	.067	.062
Hospitalized	69	39.7	45	50.6	57	23.6	23	34.3	.214	.149
Received antibiotics in facility	55	33.7	24	28.6	114	50.0	28	45.2	.150	.003
Received CPR in facility	5	2.9	3	3.3	4	1.6	3	4.6	.941	.921
911 called on last day of life	30	18.0	31	35.6	8	3.3	9	13.6	.006	.010
Palliative interventions during the last month of life										
Special attention to moving and positioning	56	32.0	26	28.3	102	41.6	29	43.3	.903	.956
Received hospice services	109	64.5	46	51.7	120	55.0	28	45.2	.123	.183
Circumstances of death										
Location of death ^c										
Facility, private room	109	63.0	44	47.8	43	17.6	17	26.2	.198	<.001
Facility, shared room	37	21.4	17	18.5	184	75.1	38	58.5		
Hospital	24	13.9	29	31.5	17	6.9	9	13.8	.005	.509
Other	3	1.7	2	2.2	1	0.4	1	1.5		

(Table 3 continues on next page)

Table 3. (Continued)

Item	RC-AL Facility				NH				<i>p</i> Value of Comparison by	
	Decedents With Dementia		Decedents Without Dementia		Decedents With Dementia		Decedents Without Dementia			
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	Dementia Status	Facility Type
Companionship at death ^d										
Someone else present	103	60.9	53	59.6	156	66.4	42	65.6	*	
Died alone	41	24.3	18	20.2	40	17.0	11	17.2	.635	.180
Staff did not know	25	14.8	18	20.2	39	16.6	11	17.2		

Notes: For the study sample, $N = 581$. Facility type is among those with dementia. RC-AL = residential care–assisted living; NH = nursing home; IV = intravenous; CPR = cardiopulmonary resuscitation. For effectiveness of hygiene care and for skin ulcers, the Dementia \times Facility Type interaction was $p < .05$ for these characteristics. *For effectiveness of hygiene care, the value for dementia versus cognitively intact is $p = .004$ in RC-AL and $p = .024$ in NH; for skin ulcer, the value for dementia versus cognitively intact is $p = .003$ in RC-AL and $p = .566$ in NH. The p value for the score test are from logistic regression with a given measure of end-of-life experience as the dependent variable and dementia status and facility type (RC-AL vs NH) as predictors, and controlling for state, decedent age, and number of dependencies in activities of daily living, using generalized estimating equations and specifying an exchangeable correlation matrix to account for clustering of residents within facilities.

^aHere, “not effectively treated” refers to an ineffective treatment (vs “never an issue” and “none”); “none” is in comparison with any pain or shortness of breath.

^bThere was a change in skip pattern midway through data collection; thus, IV fluids and use of feeding tube are unknown for 115/581 = 19.7% of the sample; other items are missing for <5% of the sample.

^cThe first comparison is private room versus shared room in the facility (individuals who died in the hospital or other location are excluded); the second is hospital versus facility, whether shared or private room (those who died in another location are excluded).

^dThe comparison is died alone versus someone present at death; those for whom the staff did not know whether the resident was alone were excluded.

tia to be more satisfied with physician communication. Finally, overall satisfaction with care did not differ between families of persons dying with dementia and those of decedents who were cognitively intact.

Dying With Dementia in RC-AL Versus NH

When we compare the staff informant reports of experiences of dying and palliative care for persons with dementia in RC-AL facilities with those of persons in NHs, again controlling for state, age, and number of ADL dependencies, we note several differences. As is displayed in Table 3, physical restraints were far more common in NHs (92% vs 66%, $p < .001$), but the use of sedative medication was not. Nutritional supplements tended to be used more commonly by NHs (88% vs 68%, $p = .003$), and parallel trends are present regarding the use of intravenous fluids (11% vs 4%, $p = .014$) and feeding tubes (7% vs 1%, $p = .062$). Similarly, antibiotic use tended to be reported more frequently in NH residents dying with dementia (50% vs 34%, $p = .003$). In contrast, RC-AL facilities tended to call 911 on the last day of life (18% vs 3%, $p < .010$). Also, RC-AL residents more often experienced a disease course that was interpreted as a series of ups and downs (34% vs 20%; $p < .001$).

A comparison of family informant data (Table 4) reveals relatively few significant differences between the experience of dying with dementia in NHs and

in RC-AL settings in terms of family involvement, advance care planning, and decision making regarding interventions. However, we noted strong trends toward differences in the area of physician communication, with RC-AL respondents being more often familiar with the resident's physician (95% vs 84%, $p = .015$), having been more likely to have met face to face with the physician (79% vs 62%, $p = .010$), and having been more likely to report more favorable family–physician communication scores ($M = 1.78$ vs 1.52, $p = .009$).

Discussion

Prior to beginning this study, one of our concerns was that persons with dementia in long-term-care settings might receive lower quality end-of-life care, because they are often unable to advocate for themselves or to effectively communicate with staff and family. Sachs and colleagues (2004), for example, reported that inadequate pain treatment, reduced hospice use, and overuse of feeding tubes are common among persons with dementia. Although persons with dementia were less likely to participate in decisions about care, our overall results suggest that the quality of palliative care provided may not differ by dementia status. Facility staff reported no significant differences in rates of use of nutritional supplements, intravenous fluids, and feeding tubes, and in attention to moving and positioning; in addition, families reported a similar frequency of

Table 4. Experience of Dying and Palliative Care Reported by Family Members of Residents Who Died With and Without Dementia in RC-AL Communities and NHs

Item	RC-AL Facility				NH				<i>p</i> Value of Comparison by	
	Decedents With Dementia		Decedents Without Dementia		Decedents With Dementia		Decedents Without Dementia		Dementia Status	Facility Type
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%		
Family involvement in last month of life										
Days visited in last month*	16.2	10.9	13.3	9.7	15.5	10.7	17.4	10.5	.684	.218
Ever spoke to resident by phone	9	9.0	31	62.0	10	9.3	14	45.2	<.001	.702
Days spoke with staff about Resident*	17.4	10.4	12.0	9.7	16.2	10.6	16.1	10.8	.178	.144
Family present at death	38	40.4	20	43.5	40	40.8	7	23.3	.314	.732
Most influential person in care decisions										
Resident ^a	27	27.0	22	45.8	24	22.4	7	24.1	.047	.152
Family	68	68.0	23	47.9	79	73.8	22	75.9		
Physician	2	2.0	0	0.0	0	0.0	0	0.0		
Nonphysician staff	3	3.0	3	6.3	4	3.7	0	0.0		
Family involvement in care (at least once a week)										
Helped with bathing, toileting, or dressing	17	16.8	11	22.4	17	16.0	6	20.0	.387	.566
Helped with grooming	27	27.0	9	18.4	37	34.9	13	43.3	.714	.744
Helped decedent walk in facility	39	39.0	18	36.7	43	40.6	12	40.0	.503	.764
Was involved at mealtime	61	61.0	23	46.9	60	56.6	16	53.3	.810	.239
Helped with financial, legal, or other management activities	79	79.0	34	69.4	72	67.9	20	66.7	.259	.011
Monitored or oversaw staff care	86	86.0	39	79.6	89	84.0	23	76.7	.478	.350
Physician communication with family during the last month of life										
Family familiar with doctor	95	95.0	45	90.0	91	84.3	26	86.7	.704	.015
Family ever met doctor	79	79.0	41	82.0	66	61.7	17	56.7	.640	.010
Family–doctor communication score*	1.78	1.05	2.19	0.90	1.52	1.01	1.50	0.95	.035	.009
Advance care planning										
Resident able to participate in decisions about care	11	11.0	25	50.0	8	7.4	15	50.0	<.001	.212
Discussed death or dying with resident	57	57.0	33	67.3	47	43.5	22	73.3	.030	.086
Had durable health care POA	96	96.0	46	92.0	101	93.5	27	90.0	.988	.485
Extent resident preferences known										
Living will ^b	93	92.1	43	87.8	92	86.0	21	70.0	.097	.252
No document, knew preferences	6	5.9	2	4.1	9	8.4	8	26.7		
No document, did not know preferences	2	2.0	4	8.2	6	5.6	1	3.3		
Decision making regarding interventions										
Decision made about: CPR	89	89.0	44	91.7	97	90.7	24	82.8	.975	.837
Decided to do CPR ^c	2	2.0	2	4.2	3	2.8	2	6.9	.291	.716
Feeding tube	82	82.8	39	81.3	89	83.2	21	72.4	.542	.782
Decided to use feeding tube	3	3.1	0	0.0	8	7.6	2	6.9	.561	.078
Comfort measures only	85	85.9	39	83.0	95	88.8	22	75.9	.274	.660
Decided to use comfort measures only	71	71.7	35	74.5	79	73.8	20	69.0	.724	.974

(Table 4 continues on next page)

Table 4. (Continued)

Item	RC-AL Facility				NH				<i>p</i> Value of Comparison by	
	Decedents With Dementia		Decedents Without Dementia		Decedents With Dementia		Decedents Without Dementia			
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	Dementia Status	Facility Type
Family global impressions of care during last month of life										
Assessment of overall quality of care										
Poor or fair	10	10.0	7	14.3	8	7.5	4	13.3		
Good	18	18.0	5	10.2	37	34.6	14	46.7		
Very good ^d	72	72.0	37	75.5	62	57.9	12	40.0	.288	.304
Would have preferred more involvement in care	22	22.0	14	28.6	30	28.0	11	36.7	.438	.235

Notes: For the study sample, *N* = 293. Facility type comparison are among those with dementia. RC-AL = residential care-assisted living; NH = nursing home; POA = power of attorney; CPR = cardiopulmonary resuscitation. The *p* value for the score test are from logistic regression with a given measure of end-of-life experience as the dependent variable and dementia status and facility type (RC-AL vs NH) as predictors, and controlling for state, decedent age, and number of dependencies in activities of daily living, using generalized estimating equations and specifying an exchangeable correlation matrix to account for clustering of residents within facilities. All values are shown as number or percentages, except for those with an asterisk (*), which are mean (standard deviation).

^aCould be resident by himself or herself or through advance directives; statistical comparisons compare this group with all other groups combined.

^bBecause of the small number not reporting a living will, this group is compared with the other two groups combined.

^cBecause of the small number of events, the adjusted model does not converge; the *p* value for dementia status is therefore adjusted only for facility type; the *p* value for facility type among the dementia group is unadjusted.

^dThese tests compare those persons rating care as very good compared with the combination of those rating care as poor, fair, or good.

discussions and decisions regarding palliative care measures. The reported prevalence of ineffectively treated pain, though slightly higher among persons with dementia, was not significantly different between groups, and inadequately treated shortness of breath was more common among cognitively intact decedents. Furthermore, family visitation rates did not differ by dementia status; persons with dementia were no more likely to die alone; and hospice use did not differ between the two groups. Finally, family assessments of the overall quality of care did not differ by dementia status, a finding that is similar to the recent report of Engel and colleagues (2006).

Our findings are in contrast to those of Mitchell and colleagues (2004), who identified a consistent pattern for New York NH residents with dementia to be receiving less palliative care than a comparison group of residents with advanced cancer. They found that residents with advanced dementia had a lower prevalence of orders not to resuscitate, hospitalize, or tube feed, and higher levels of feeding tube use, test performance, and restraint use. None of these patterns were evident in our data, however, and several explanations are possible for this inconsistency. First of all, it is possible that care patterns have changed, as Mitchell's data are 8 years older than ours, and palliative care for end-stage dementia has become more commonplace in recent years. Additionally, Mitchell's choice of persons dying of cancer as the comparison group affects her findings, as cancer tends to have a more recognized terminal disease trajectory than dementia (Chen, Chan, Kiely,

Morris, & Mitchell, 2007), thereby magnifying differences in care. Furthermore, life-sustaining treatments, such as antibiotics or intravenous fluids, tend to be effective in the short run in persons with dementia but not in terminal cancer, further complicating decision-making processes (Sachs et al., 2004). Therefore, we feel that, in both NH and RC-AL facilities, differences in palliative care between persons with dementia and those who are cognitively intact may be far less prominent than have been previously reported.

The high rates of hospice service use we observed among persons dying with dementia in both RC-AL settings (65%) and NHs (55%) is particularly refreshing, as this indicates a marked trend upward from the virtual nonuse by persons with dementia reported by Hanrahan and Luchins in 1995 and the lower rates that we identified 5 years prior to the current study (Sloane et al., 2003). An unresolved question is whether hospice services are initiated early enough in dementia; indeed, some of the differences noted by Mitchell and colleagues (2004) but not by our study could have reflected the earlier initiation of palliative care in cancer than in dementia. Thus, the issue in quality end-stage dementia care is no longer whether or not to use hospice, but instead whether to initiate palliative care earlier and more gradually; this issue is a major point of emphasis of the clinical practice guidelines developed by the National Consensus Project for Quality Palliative Care (National Consensus Project, 2004).

The high reported rates of physical restraint and

sedative use by persons with dementia is troublesome. Indeed, the rates of non-bedrail physical restraint use for all subgroups studied (46% and 68% for persons with dementia in RC-AL facilities and NHs, and 17% and 48% for persons without dementia in RC-AL facilities and NHs, respectively) merits further study. Given that physical restraint use in NHs has been strongly discouraged since the Nursing Home Reform Act of 1987, and that rates of approximately 10% have been reported in general studies of NH residents (Phillips, Spry, Sloane, & Hawes, 2000; also see Castle, Degenholtz, & Engberg, 2005), both demented and nondemented patients who are dying appear to disproportionately be physically restrained, with dementia patients significantly more at risk ($p = .002$). This issue merits further investigation. Reported rates of sedative use were also higher among persons with dementia than among those who were nondemented; however, sedatives are often considered appropriate for symptom relief as part of the care of persons who are imminently dying (National Consensus Project, 2004), and so these rates and differences are difficult to interpret. Therefore, further, case-specific research is needed in this area.

As is noted in the new End-of-Life Care Guidelines from the Alzheimer's Association (2007) and in the article by Sachs and colleagues (2004), the role of family in decision making and communication with health care providers are elements that most strongly distinguish end-of-life care of persons with dementia from those who are cognitively intact. Thus, it was encouraging to see that family participation in, and the frequency of completion of, discussions involving life-sustaining treatments and palliative care interventions appeared to be just as frequent among decedents with dementia as those who were cognitively intact. Levels of physician-family communication also appeared to be similar (Table 4), although in this context perhaps greater communication with family overall would be preferred, and the comparatively low family-physician communication scores suggest a need for improvement.

Decisions to use a palliative care approach were more common among persons who had dementia. Thus, persons who were cognitively intact were more likely to have died in the hospital and to have had emergency services called on the day of death. Quite possibly, such a difference in the use of life-prolonging care may be medically appropriate, as many dementia care experts have advocated for a palliative focus to care of end-stage Alzheimer's disease (Volicer, 2001; Wolf-Klein, Pekmezaris, Chin, & Weiner, 2007). Furthermore, unexpected acute events may have occurred more frequently among persons who were cognitively intact, as our study noted a nonsignificant trend for staff caring for persons dying with dementia to report stable health, followed by a relatively sudden terminal event (unadjusted $p = .025$; adjusted $p = .212$).

Another concern we had prior to initiating the study was that the quality of end-of-life care in RC-AL facilities might be lower than that provided in NHs, because RC-AL facilities tend to have fewer professional staff and to be designed largely for less impaired residents. Differences in end-of-life care by facility type were indeed noted, some of which are expected because of the different care environments, but no pattern of differences in quality is evident. RC-AL caters more to a private-pay clientele and less-impaired residents, and provides fewer medical services, so the findings (Table 3) that decedents with dementia in RC-AL facilities more often had private rooms and received fewer nonpalliative medical services (i.e., nutritional supplements, antibiotics, and 911 calls on the last day of life) are not new observations (Sloane et al., 2003). RC-AL residents with dementia were also less frequently physically restrained, and family members of RC-AL decedents reported better communication with physicians. Symptom care did not seem to differ, however, with the striking exception of skin ulcers, which were significantly more common among demented than nondemented persons in RC-AL facilities ($p = .003$) but not in NHs ($p = .566$). In summary, these data suggest a trade-off between settings related to various components of care, and that neither is clearly superior to the other.

A number of potential limitations of the study should be noted, many of which are due to the retrospective nature of the study design. Our method of determining who did and did not have dementia was indirect, excluded approximately 14% of the sample, and could have led to some misclassification. However, because terminal delirium is common in dying persons, the questions that we asked, including inquiring about status 3 months before death, represent a valid (albeit indirect) method of identifying persons who died with Alzheimer's disease or another dementia. Furthermore, even expert, in-person assessments fail to classify the dementia status of as many as 20% of long-term-care residents, so excluding 14% is in line with established evidence (Magaziner et al., 2000). Finally, although misclassification is never preferred, such a bias will tend to reduce rather than inflate the statistical significance of findings, and therefore it does not threaten the validity of the positive associations noted.

Another potential limitation of the study is nonresponse. Because family interview data were available for only about half of the enrolled decedents, responses could have been biased toward, for example, family members who were more involved in care. The data available to us suggest that this is true, as family were present at death for 44% of those with a family interview, compared with 34% of those without ($p = .026$), and both NH decedents and African American decedents were less likely to have a family interview. In addition, the possibility that respondent nonresponse may have

varied by dementia status or facility type is another source of potential selection bias.

We should note that we have conducted multiple statistical tests, and that therefore the likelihood of identifying spuriously “significant” results is high; for this reason we focused our discussion on relationships that were significant at the $p < .01$ level or that demonstrated consistent trends across multiple measures within a domain. Furthermore, unmeasured or uncontrolled sources of confounding between the dementia and nondementia or the NH and RC-AL samples could have been present. Other potential limitations of the study derive from the use of proxy respondents; thus, staff could have underreported the prevalence of inadequate care, particularly in discussing symptoms, and issues of reliability could have lead to inflation in the variability of estimates; these are possibilities that, if present, would have tended to reduce the likelihood of finding significant differences.

Nevertheless, to the best of our knowledge the results presented here represent the largest and most comprehensive study of dying with dementia in long-term care reported to date. They provide reassurance that, in general, both NHs and RC-AL settings appear to provide quality, appropriate care to dying persons with dementia, and that this care is generally provided in the facility. They also identify potential foci for care improvement initiatives and further research, such as the use of physical restraints, prevention of skin ulcers in RC-AL facilities, and physician–family communication.

References

- Alzheimer's Association. (2007). *Dementia care practice recommendations for assisted living residences and nursing homes, Phase 3: End-of-life care*. Retrieved December 24, 2007, from http://www.alz.org/documents/DCPRPhase3_.pd.
- Biola, H., Sloane, P. D., Williams, C. S., Daaleman, T. P., Williams, S. W., & Zimmerman, S. (2007). Physician communication with family members of long-term care residents at the end of life. *Journal of the American Geriatrics Society*, 55, 846–856.
- Bradley, E. H., Peiris, V., & Wetle, T. (1998). Discussions about end-of-life care in nursing homes. *Journal of American Geriatrics Society*, 46, 1235–1241.
- Castle, N. G., Degenholtz, H., & Engberg, J. (2005). State variability in indicators of quality of care in nursing facilities. *Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 60A, M1173–M1179.
- Centers for Disease Control and Protection, National Center for Health Statistics. (2002). *The National Nursing Home Survey: 1999 summary* (CDC Vital and Health Statistics Series 13, No. 152). Washington, DC: Centers for Disease Control and Protection.
- Chen, J. -H., Chan, D. -C., Kiely, D. K., Morris, J. N., & Mitchell, S. L. (2007). Terminal trajectories of functional decline in the long-term care setting. *Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 62A, M531–M536.
- Diggle, P. J., Heagerty, P., Liang, K. -Y., & Zeger, S. (2002). *The analysis of longitudinal data* (2nd ed.). Oxford: Oxford University Press.
- Engel, S. C., Kiely, D. K., & Mitchell, S. L. (2006). Satisfaction with end of life care for nursing home residents with dementia. *Journal of the American Geriatrics Society*, 54, 1567–1572.
- Ferrell, B. R. (2005). Overview of the domains of variables relevant to end-of-life care. *Journal of Palliative Medicine*, 8, 22–29.
- Hanrahan, P., & Luchins, D. J. (1995). Access to hospice programs in end-stage dementia: A national survey of hospice programs. *Journal of the American Geriatrics Society*, 43, 56–59.
- Hanson, L. C., Danis, M., Mutran, E., & Keenan, N. L. (1994). Impact of patient incompetence on decisions to withhold life-sustaining treatment. *American Journal of Medicine*, 97, 235–241.
- Liang, K. Y., & Zeger, S. L. (1986). Longitudinal data analysis using generalized linear models. *Biometrika*, 73, 13–22.
- Magaziner, J., German, P., Zimmerman, S. L., Hebel, J. R., Burton, L., Gruber-Baldini, A. L., et al. (2000). The prevalence of dementia in a statewide sample of new nursing home admissions aged 65 and older: Diagnosis by expert panel. *The Gerontologist*, 40, 663–672.
- Mitchell, S. L., Kiely, D. K., & Hamel, M. B. (2004). Dying with advanced dementia in the nursing home. *Archives of Internal Medicine*, 164, 321–326.
- Mitchell, S. L., Teno, J. M., Miller, S. C., & Mor, V. (2005). A national study of the location of death for older persons with dementia. *Journal of the American Geriatrics Society*, 53, 299–305.
- National Center for Assisted Living. (2001). *Assisted living resident profile*. Retrieved August 8, 2005, from www.ncal.org/about/resident.htm.
- National Consensus Project for Quality Palliative Care. (2004). Clinical practice guidelines for quality palliative care, executive summary. *Journal of Palliative Medicine*, 7, 611–627.
- Phillips, C. D., Spry, K. M., Sloane, P. D., & Hawes, C. (2000). Use of physical restraints and psychotropic medications in Alzheimer special care units in nursing homes. *American Journal of Public Health*, 90, 92–96.
- Preisser, J. S., & Koch, G. G., (1997). Categorical data analysis in public health. *Annual Review of Public Health*, 18, 51–82.
- Richardson, S. S., Sullivan, G., Hill, A., & Yu, W. (2007). Use of aggressive medical treatments near the end of life: Differences between patients with and without dementia. *Health Services Research*, 42(1 Part 1), 183–200.
- Sachs, G. A., Shega, J. W., & Cox-Hayley, D. (2004). Barriers to excellent end-of-life care for patients with dementia. *Journal of General Internal Medicine*, 19, 1057–1063.
- Sampson, E. L., Ritchie, C. W., Lai, R., Raven, P. W., & Blanchard, M. R. (2005). A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia. *International Psychogeriatrics*, 17, 31–40.
- Schonwetter, R. S., Han, B., Small, B. J., Martin, B., Tope, K., & Haley, W. E. (2003). Predictors of six-month survival among patients with dementia: An evaluation of hospice Medicare guidelines. *American Journal of Hospice and Palliative Care*, 20, 105–113.
- Sloane, P. D., Zimmerman, S., Hanson, L., Mitchell, C. M., Reidel-Leo, C., & Custis-Buie, V. (2003). End-of-life care in assisted living and related residential care settings: Comparison with nursing homes. *Journal of the American Geriatrics Society*, 51, 1587–1594.
- Volicer, L. (2001). Management of severe Alzheimer's disease and end-of-life issues. *Clinics in Geriatric Medicine*, 17, 377–391.
- Volicer, L., Hurley, A. C., & Blasi, Z. V. (2001). Scales for the evaluation of end-of-life care in dementia. *Alzheimer Disease and Associated Disorders*, 15, 194–200.
- Wolf-Klein, G., Pekmezaris, R., Chin, L., & Weiner, J. (2007). Conceptualizing Alzheimer's disease as a terminal medical illness. *American Journal of Hospice and Palliative Care*, 24, 77–82.
- Zimmerman, S., Sloane, P. D., & Eckert, J. K. (2001). *Assisted living: Needs, practices and policies in residential care for the elderly*. Baltimore: Johns Hopkins University Press.
- Zimmerman, S., Sloane, P. D., Eckert, J. K., Gruber-Baldini, A. L., Morgan, L. A., Hebel, J. R., et al. (2005). How good is assisted living? Findings and implications from an outcomes study. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 60B, S195–S204.
- Zimmerman, S., Sloane, P. D., Williams, C. S., Dobbs, D., Ellajosyula, R., Braaten, A., et al. (2007). Residential care/assisted living staff may detect undiagnosed dementia using the Minimum Data Set Cognition Scale (MDS-COGS). *Journal of the American Geriatrics Society*, 55, 1349–1355.

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